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## **Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK (the International Cancer Benchmarking Partnership)**

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# Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK (the International Cancer Benchmarking Partnership): do they contribute to differences in cancer survival?

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**Background:** There are wide international differences in 1-year cancer survival. The UK and Denmark perform poorly compared with other high-income countries with similar health care systems: Australia, Canada and Sweden have good cancer survival rates, Norway intermediate survival rates. The objective of this study was to examine the pattern of differences in cancer awareness and beliefs across these countries to identify where these might contribute to the pattern of survival.

**Methods:** We carried out a population-based telephone interview survey of 19 079 men and women aged  $\geq 50$  years in Australia, Canada, Denmark, Norway, Sweden and the UK using the Awareness and Beliefs about Cancer measure.

**Results:** Awareness that the risk of cancer increased with age was lower in the UK (14%), Canada (13%) and Australia (16%) but was higher in Denmark (25%), Norway (29%) and Sweden (38%). Symptom awareness was no lower in the UK and Denmark than other countries. Perceived barriers to symptomatic presentation were highest in the UK, in particular being worried about wasting the doctor's time (UK 34%; Canada 21%; Australia 14%; Denmark 12%; Norway 11%; Sweden 9%).

**Conclusion:** The UK had low awareness of age-related risk and the highest perceived barriers to symptomatic presentation, but symptom awareness in the UK did not differ from other countries. Denmark had higher awareness of age-related risk and few perceived barriers to symptomatic presentation. This suggests that other factors must be involved in explaining Denmark's poor survival rates. In the UK, interventions that address barriers to prompt presentation in primary care should be developed and evaluated.

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<sup>14</sup>See Appendix A.

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International comparisons show wide differences in cancer survival between high-income countries with good cancer registration systems and good access to health care (Berrino *et al*, 2007; Coleman *et al*, 2008). The International Cancer Benchmarking Partnership (ICBP) was set up to examine and explain survival differences between Australia, Canada, Denmark, Norway, Sweden and the UK. For cancers of the lung, breast, bowel and ovary diagnosed in 1995–2007, Australia, Canada and Sweden had the highest survival and Denmark and the UK the lowest; Norway had intermediate survival (Coleman *et al*, 2011).

Survival differences between these countries were largely explained by differences in 1-year survival (Coleman *et al*, 2011), which may be a marker of late stage at diagnosis for some cancers. High-resolution studies of survival suggest that international differences are partly explained by differences in stage at diagnosis for some cancers (Gatta *et al*, 2000; Sant *et al*, 2003, 2007; Bouvier *et al*, 2010). Although there is emerging evidence that differences in stage distribution do not explain all the variation in short-term survival (Maringe *et al*, 2012 and Michel Coleman, personal communication), patient delay in presentation with symptoms and health care system delay in referral or diagnosis are, nevertheless, considered likely to contribute to later stage at diagnosis (Richards *et al*, 1999). There is evidence for an important role for patient delay (Neal *et al*, 2008; Neal, 2009).

Systematic reviews have found that low awareness of symptoms is associated with patient delay for a range of common cancers (Ramirez *et al*, 1999; Macleod *et al*, 2009). Other potential influences on time to presentation include negative beliefs about cancer outcomes (von Wagner *et al*, 2011) or barriers to symptomatic presentation (Robb *et al*, 2009; Forbes *et al*, 2011) and poor awareness of the risk of cancer. In particular, there is evidence that older people are not aware that the risk of cancer increases with age (Grunfeld *et al*, 2002) and are more likely to delay presentation (Ramirez *et al*, 1999). In the UK, lower awareness of cancer symptoms and more barriers to help-seeking have been associated with longer anticipated delay in help-seeking (Robb *et al*, 2009; Simon *et al*, 2010).

An individual's cancer awareness and beliefs may also influence whether they are referred promptly for investigation by their GP or whether they receive effective treatments promptly. People with high levels of awareness and positive beliefs about cancer outcomes may be more likely to demand referral or may be more likely to take up the offer of more aggressive treatment (Mitchell *et al*, 2007).

We aimed to examine whether people living in countries with lower cancer survival (UK, Denmark) had lower cancer awareness, more negative beliefs about cancer or more barriers to symptomatic presentation than people in countries with higher cancer survival (Australia, Canada, Sweden).

## MATERIALS AND METHODS

**Overview.** We carried out telephone surveys of people aged  $\geq 50$  years in Australia (two states: New South Wales and Victoria), Canada (four provinces: Alberta, British Columbia, Manitoba, Ontario), Denmark, Sweden (two areas in central Sweden: Uppsala-Örebro, Stockholm-Gotland), Norway and the UK (three countries: England, Northern Ireland and Wales) to match the areas included in the ICBP analyses of cancer survival (Coleman *et al*, 2011). We aimed to achieve samples representative of the populations of people aged  $\geq 50$ . We selected this age group because population-level cancer survival largely reflects survival in the over-50s, in whom cancer is the commonest. We measured

cancer awareness and beliefs using the newly developed Awareness and Beliefs about Cancer (ABC) measure (Simon *et al*, 2012). We examined whether the pattern of cancer awareness and beliefs followed the pattern expected from differences in cancer survival and carried out statistical tests of differences between each country and the UK.

**Measures.** The development, validation and structure of the ABC are described in our accompanying paper (Simon *et al*, 2012). The items in the ABC were informed by theoretical frameworks, such as the Health Belief Model, and drew from other measures previously used in population surveys (Paul *et al*, 2006; Stubbings *et al*, 2009; Park and Clery, 2010) but were designed to identify key items that could differ between countries rather than test any one theoretical model. We aimed to harmonise the measures across all six countries focusing on conceptual and cultural equivalence rather than relying simply on verbatim translation. After cognitive testing and assessment of test–retest reliability and content validity in UK English, the ABC was translated and made culturally appropriate for each country. A panel of experts adapted the measure to make it locally appropriate in collaboration with international colleagues so that equivalence of meaning was not lost, then cognitive testing in each country was carried out. For the French Canadian, Danish, Norwegian and Swedish versions, we estimated equivalence of meaning with the English version quantitatively, and then carried out several further cognitive interviews among bilingual speakers of English and each of the four languages.

In this paper, we provide results of international comparisons for items related to recognition of cancer symptoms (from a list of 11 possible symptoms), awareness that cancer risk is higher in people aged  $\geq 70$  years than at a younger age, beliefs about barriers to symptomatic presentation (items asking whether embarrassment, fear about what the doctor might find, worry about wasting the doctor's time and being too busy might put them off going to the doctor) and negative beliefs about cancer outcomes (items asking whether participants agreed that 'many people with cancer can expect to continue with normal activities and responsibilities', 'cancer can often be cured' and 'a diagnosis of cancer is a death sentence').

We also collected data on age, sex, language spoken at home, relationship status, experience of cancer (self, family and friends), self-rated health and level of education, mapping categories of education in each country onto the International Standard Classification of Education (UNESCO, 2006).

**Data collection.** Data collection were carried out by Ipsos MORI using computer-assisted live telephone interviews. All men and women aged  $\geq 50$  years living in private households and able to understand an official language of the country were eligible.

In Australia, Canada and the UK, the sampling frames were commercially available electronic landline telephone listings, because sampling frames of all adults aged  $\geq 50$  years are not freely available. Telephone numbers were randomly selected in a number proportionate to population size of each region. The final two digits of each selected number were replaced with two random numbers, which brought unlisted numbers into the sampling frame. If the person answering the telephone reported that one or more people aged  $\geq 50$  years lived in the household, that household was considered eligible. If more than one person aged  $\geq 50$  years lived in the household, the Rizzo method was used to select one person to be interviewed; this gives an equal chance of selection to all eligible people living in the household (Rizzo *et al*, 2004). In Denmark, Norway and Sweden, the sampling frames were national population registers, which include name, address and date of birth. We randomly selected people aged  $\geq 50$  years (without stratifying by geography) and identified their telephone

numbers (mobile or landline) from electronic telephone listings using their names and addresses.

Interviewers were randomly allocated telephone numbers. Each telephone number was called up to seven times at different times of day. Experienced interviewers listened to a random 10% of calls to assess quality and provide performance feedback. The order of the items in 'lists' were rotated randomly to avoid bias introduced by ordering.

Interviewers were trained to undertake the survey accurately, sensitively and consistently. Interviews in Denmark, Norway, Sweden and among French-speaking Canadians were carried out by native language speakers. Interviewers offered participants contact details of a local cancer support charity or other agency if they showed any sign of distress.

Interviews were carried out in Australia, Denmark and the UK from May to July 2011, in Canada in June and July 2011 and in Norway and Sweden in August and September 2011, to avoid summer holiday periods, which were different in each country.

**Sample size.** We aimed to achieve a sample size of 2000 participants in each country. We based sample size calculations on the results of a UK survey of cancer awareness (Robb *et al*, 2009), in which 45% recognised a persistent cough as a warning sign for cancer. A sample size of 2000 in each country was found to be sufficient to show a 6% difference in recognition of persistent cough as a symptom of cancer between the UK and another country, with 90% power at the 5% level of significance.

**Analysis.** We calculated response rates using the American Association for Public Opinion Research (AAPOR) conventions, to provide comparable response rates after allowing for variations in survey methods (The American Association of Public Opinion Research, 2011). This is important because in three of the countries (Australia, Canada and the UK) we did not know the denominator of eligible people and therefore could not calculate the response rate in the usual way. We calculated the 'minimum response rate' as the number of complete interviews divided by the number of all possible interviews (the number of interviews among eligible people plus the number of households where eligible people were known to live, but where the interview could not be completed (e.g., refusal, interview broken off) plus the number of all households of unknown eligibility). It represents the response rate assuming that all households that we could not assess for eligibility were eligible (equivalent to AAPOR response rate formula 1). It is likely to underestimate response rates because it is likely that many households were ineligible. We also calculated the 'estimated response rate' as the number of completed interviews divided by the estimated number of eligible individuals, based on the proportion of households that were eligible out of those assessed for eligibility (equivalent to AAPOR response rate formula 3).

Using responses to the 11 items on cancer symptom awareness (unexplained lump or swelling, persistent unexplained pain, unexplained bleeding, a persistent cough or hoarseness, a change in bowel or bladder habits, a persistent difficulty in swallowing, a change in the appearance of a mole, a sore that does not heal, unexplained night sweats, unexplained weight loss, unexplained tiredness; response categories: yes/no), we computed the total number of symptoms recognised.

We calculated aggregate scores for beliefs about barriers to symptomatic presentation and beliefs about cancer outcomes, based on results of the factor analysis as described in our linked paper (Simon *et al*, 2012). Briefly, we generated two new variables, one based on four barrier items: too embarrassed, too busy, worried about wasting the doctor's time, worried about what the doctor might find) and the other based on three belief items ('cancer can often be cured', 'a diagnosis of cancer is a death sentence', 'people with cancer can expect to continue with normal activities and responsibilities'). We carried out factor analysis of the

inter-correlations of the items that identified the underlying theoretical factors that accounted for most of the common variation; these were used to weight the items before summing into aggregate scores. For both the aggregate scores, we standardised the results so that the minimum score was 0 and the maximum 50, a higher score reflecting more negative beliefs or more barriers, and calculated means and 95% confidence intervals.

We also calculated the proportion of participants who agreed or disagreed with each individual barrier item (combining response categories 'yes often' and 'yes sometimes') and each individual belief about cancer outcomes (combining the response categories 'strongly agree' with 'tend to agree' and 'tend to disagree' with 'strongly disagree').

We weighted percentages and means to allow for design effects introduced by variations between countries in sampling methods and household size (further details provided in online supplement; Supplementary Table S2 shows the sources used to apply non-representativeness weights and variables used in weighting). We age-sex-standardised weighted percentages and adjusted means for age and sex to allow for differences in age-sex distribution between the countries' samples, using the European Standard Population. We fitted multivariable models (logistic or linear regressions as appropriate) to examine the associations between the cancer awareness and belief variables (mean number of cancer symptoms recognised, awareness of age-related risk of cancer, beliefs about cancer outcomes and barriers to symptomatic presentation) and country, with UK as reference category.

Bootstrapping was conducted for the linear regression analyses, because the assumption that the residuals were normally distributed did not hold. This involved taking multiple samples with replacement and using these multiple samples to generate the regression coefficients and standard errors (Carpenter and Bithell, 2000).

We weighted the odds ratios and means to allow for design effects (further details in the online supplement). Our first model included age (50–59, 60–69,  $\geq 70$  years) and sex, and the second included educational level, experience of cancer (self or among family and friends, none), living alone (yes, no) and self-reported health (good, fair, poor), to examine the extent to which differences in these might explain the differences between the countries in levels of cancer awareness or beliefs. Data were analysed using SPSS for Windows, Release 15.0.0, 2006 (Chicago, IL, USA).

Where particular demographic groups were over- or under-represented (based on the demographic profile of the population aged  $\geq 50$  years in each country obtained from routine data sources), we then weighted the percentages, means and odds ratios for these. In practice, this meant that we weighted for age, sex and education in every country (except for education in Denmark); we also weighted for marital status in Northern Ireland and Wales, ancestry (Canada), country of birth and metropolitan/rural residence (Australia), country of origin (Norway and Sweden) and region (Northern Ireland and Wales; further details provided in the online supplement; see Supplementary Table S2).

## RESULTS

**Response.** Nineteen thousand and seventy nine people completed the ABC measure. Response rates are shown in Table 1. The minimum response rate was lowest in the countries where random digit dialling was used, because the number of households for which we did not know eligibility was high. In the Scandinavian countries, nearly all households telephoned were eligible, because we used population registers to select households where someone aged  $\geq 50$  years lived. The estimated response rates were very

Table 1. Response rates

	Australia	Canada	Denmark	Norway	Sweden	UK
Total number of households with connected telephone numbers approached	35 730	46 672	5369	8921	7411	80 210
Number of households of unknown eligibility <sup>a</sup>	20 719	34 828	899	1922	1901	55 979
Number of households of known eligibility	15 011	11 844	4470	6999	5510	24 231
Number of households in which the individual declined to take part either during or after assessment of eligibility	433	1195	2337	4726	3345	3468
Number of ineligible households <sup>a</sup>	10 119	8571	12	24	19	13 234
Number of eligible households <sup>a</sup>	4892	3273	4458	6975	5491	10 997
Proportion of households eligible among those assessed for eligibility (%)	32.6	27.6	99.7	99.7	99.7	45.4
Completed interviews	4002	2064	2000	2009	2039	6965
Minimum response rate (%) <sup>b</sup>	15.9	5.4	31.5	23.2	28.0	10.5
Estimated response rate (%) <sup>c</sup>	47.4	38.8	31.6	23.0	27.5	40.0

<sup>a</sup>A household was eligible if one or more people aged  $\geq 50$  years lived in the household.

<sup>b</sup>The minimum response rate represents the response rate assuming all households that we could not assess for eligibility were eligible, in other words the lowest possible response rate. It is calculated as the number of complete interviews divided by the number of interviews plus the number of incomplete interviews among eligible people (refusals and break-offs plus non-contacts) plus the number of all households of unknown eligibility (equivalent to the American Association for Public Opinion Research response rate formula 1).

<sup>c</sup>The estimated response rate represents the response rate after adjusting the size of the denominator for the likely proportion of households that were eligible. It is calculated by assuming that the proportion eligible among households of unknown eligibility is the same as the proportion of those tested for eligibility who were eligible (equivalent to American Association for Public Opinion Research response rate formula 3).

Table 2. Description of sample populations

	Australia			UK					
Age group (years)	New South Wales	Victoria	Canada <sup>a</sup>	Denmark	Norway	Sweden <sup>b</sup>	England	Northern Ireland	Wales
<b>Women</b>									
50–69	795 (39.7)	796 (39.8)	988 (47.9)	804 (40.2)	716 (35.6)	801 (39.3)	949 (40.2)	1092 (47.3)	952 (41.4)
$\geq 70$	457 (22.8)	472 (23.6)	342 (16.6)	261 (13.1)	216 (10.8)	310 (15.2)	517 (21.9)	378 (16.4)	431 (18.8)
Total	1252 (62.6)	1268 (63.4)	1330 (64.5)	1065 (53.3)	932 (46.4)	1111 (54.5)	1466 (62.1)	1470 (63.7)	1383 (60.2)
<b>Men</b>									
50–69	497 (24.8)	473 (23.6)	563 (27.3)	706 (35.3)	775 (38.6)	668 (32.8)	618 (26.2)	613 (26.6)	658 (28.6)
$\geq 70$	247 (12.3)	254 (12.7)	171 (8.3)	229 (11.5)	302 (15.0)	260 (12.8)	267 (11.3)	219 (9.5)	255 (11.1)
Total	744 (37.2)	727 (36.3)	734 (35.6)	935 (46.8)	1077 (53.6)	928 (45.6)	885 (37.5)	832 (36.1)	913 (39.7)
<b>All</b>									
50–69	1292 (64.6)	1269 (63.4)	1551 (75.2)	1510 (75.5)	1491 (74.2)	1469 (72.1)	1567 (66.4)	1705 (73.9)	1610 (70.0)
$\geq 70$	704 (35.2)	726 (36.3)	513 (24.9)	490 (24.6)	518 (25.8)	570 (28.0)	784 (33.2)	597 (25.9)	686 (29.9)
Missing age	5 (0.2)	6 (0.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	9 (0.4)	5 (0.2)	2 (0.1)
Total	2001 (100)	2001 (100)	2064 (100)	2000 (100)	2009 (100)	2039 (100)	2360 (100)	2307 (100)	2298 (100)
Speaks official language at home <sup>c</sup>	1780/1996 (89.2)	1711/1995 (85.8)	1990/2058 (96.7)	1985/2000 (99.3)	1970/2009 (98.1)	1969/2038 (96.6)	2315/2350 (98.5)	2287/2300 (99.4)	2288/2293 (99.8)
Educated to university degree level	623/1980 (31.5)	678/1980 (34.2)	706/2051 (34.4)	582/1994 (29.2)	927/1999 (46.4)	729/2037 (35.8)	556/2317 (24.0)	505/2267 (22.3)	506/2278 (22.2)
Married or living with partner	1096/1984 (55.2)	1102/1988 (55.4)	1201/2054 (58.5)	1514/1998 (75.8)	1453/2006 (72.4)	1432/2037 (70.3)	1215/2339 (51.9)	1286/2291 (56.1)	1281/2287 (56.0)
Experience of cancer (self, family or friend)	1655/1992 (83.1)	1644/1994 (82.4)	1758/2061 (85.3)	1705/2000 (85.3)	1696/2008 (84.5)	1664/2037 (81.7)	1876/2347 (79.9)	1801/2296 (78.4)	1890/2291 (82.5)
Self-rated health status (good/very good)	1496/1994 (75.0)	1553/1989 (78.1)	1624/2063 (78.7)	1499/1993 (75.2)	1568/2001 (78.4)	1442/2034 (70.9)	1695/2345 (72.3)	1624/2296 (70.7)	1541/2288 (67.4)

Values are n (%).

<sup>a</sup>Alberta, British Columbia, Manitoba, Ontario.

<sup>b</sup>Uppsala-Örebro, Stockholm-Gotland.

<sup>c</sup>Official languages: Australia: English (*de facto* official language); Canada: English, French; Denmark: Danish; Norway: Norwegian; Sweden: Swedish; UK: English, Welsh, Ulster Scots, Irish.



similar to the minimum response rates in the Scandinavian countries, because the proportion of ineligible households was low. The estimated response rate ranged from 23% in Norway to 47% in Australia.

#### Characteristics and representativeness of sample populations.

On average, 29% of the participants were aged  $\geq 70$  years (25% in Denmark to 36% in Australia) (Table 2); this proportion was roughly representative of the age distribution of the population (see Supplementary Table S1 online). Women were slightly over-represented (59%, vs 53% in the population aged  $\geq 50$  years), with the Canadian sample having the highest proportion of women (65%) and Norway the lowest (46%; Table 2). The proportion of participants with a university degree was the lowest in the UK (23%) and the highest in Norway (46%; Table 2). The proportion of the countries' populations aged  $\geq 50$  years with a degree ranges from 10% to 30%.

More than 96% of participants spoke an official language in all countries' samples except in Australia, where 88% spoke English, the *de facto* official language, at home. Between 52% and 76% were married or living with a partner. Across the countries, between 79% and 86% of participants reported that they had experience of cancer, either themselves or in a close friend or family member, and 67–79% rated their health status as 'good' or 'very good'.

**Cancer awareness.** The mean number of symptoms recognised out of 11 was relatively high and varied little between Wales (8.21) and Canada (8.70), with the mean in Sweden somewhat lower (7.71) (Table 3). Controlling for education slightly attenuated the differences, but the pattern remained the same. Controlling for

Table 3. Awareness of cancer symptoms and age-related risk of cancer

	Number of symptoms recognised out of 11 (95% CI) (mean adjusted for age and sex)	Knew that 70-year olds most likely to be diagnosed with cancer (rather than 30-year olds, 50-year olds or people of any age)	
		n (%) <sup>a</sup>	OR (95% CI) <sup>b</sup>
UK	8.22 (8.14–8.30)	747/6839 (13.6)	1.00 (Reference)
England	8.23 (8.13–8.33)	285/2384 (13.8)	
Northern Ireland	8.53 (8.43–8.62)	218/2267 (10.7)	
Wales	8.21 (8.12–8.31)	244/2268 (11.3)	
Denmark	8.35 (8.26–8.44)	481/1962 (24.8)	2.15 (1.83–2.53)
Norway	8.49 (8.40–8.58)	576/1981 (28.7)	2.63 (2.25–3.08)
Sweden	7.71 (7.62–7.81)	752/2015 (37.8)	4.05 (3.48–4.72)
Australia	8.34 (8.27–8.41)	563/3894 (15.5)	1.18 (1.01–1.37)
New South Wales	8.37 (8.27–8.47)	254/1956 (13.8)	
Victoria	8.29 (8.18–8.40)	309/1938 (17.9)	
Canada	8.70 (8.60–8.81)	248/2045 (13.3)	1.02 (0.83–1.24)

Abbreviations: CI = confidence interval; OR = odds ratio. Means, percentages and odds ratios for all UK countries combined, both Australian states combined and all Canadian provinces combined are weighted for unequal sampling fraction by country (UK), state (Australia) or province (Canada). All means, percentages and odds ratios are weighted for different probabilities of selection by household size.

<sup>a</sup>Directly age-sex standardised using European Standard Population.

<sup>b</sup>Adjusted for age and sex.

Table 4. Barriers to symptomatic presentation: would any of these put you off going to the doctor with a symptom that might be serious? Individual items

	n (%) <sup>a</sup>	OR (95% CI) <sup>b</sup>
<b>I would be too embarrassed</b>		
UK	1127/6937 (14.5)	1.00 (Reference)
England	332/2345 (14.3)	
Northern Ireland	431/2300 (18.1)	
Wales	364/2292 (15.4)	
Denmark	117/1998 (5.8)	0.36 (0.29–0.45)
Norway	189/2007 (9.4)	0.62 (0.51–0.75)
Sweden	184/2027 (9.2)	0.60 (0.50–0.72)
Australia	450/3980 (11.6)	0.77 (0.66–0.90)
New South Wales	231/1991 (12.1)	
Victoria	219/1989 (11.0)	
Canada	203/2063 (9.6)	0.62 (0.51–0.76)
<b>I would be worried about wasting the doctor's time</b>		
UK	2330/6935 (34.3)	1.00 (Reference)
England	788/2348 (34.3)	
Northern Ireland	775/2300 (33.6)	
Wales	767/2287 (33.5)	
Denmark	235/1995 (11.7)	0.25 (0.22–0.30)
Norway	216/2005 (10.9)	0.23 (0.20–0.27)
Sweden	189/2036 (9.3)	0.20 (0.17–0.23)
Australia	575/3983 (14.2)	0.32 (0.28–0.36)
New South Wales	283/1996 (13.8)	
Victoria	292/1987 (14.5)	
Canada	428/2062 (21.1)	0.50 (0.43–0.58)
<b>I would be worried about what the doctor might find</b>		
UK	2023/6925 (27.5)	1.00 (Reference)
England	645/2345 (27.4)	
Northern Ireland	689/2291 (29.5)	
Wales	689/2289 (29.2)	
Denmark	478/1986 (23.9)	0.83 (0.72–0.95)
Norway	390/1997 (19.8)	0.65 (0.56–0.75)
Sweden	469/2033 (23.1)	0.79 (0.69–0.90)
Australia	885/3974 (22.0)	0.73 (0.65–0.82)
New South Wales	429/1992 (21.5)	
Victoria	456/1982 (22.7)	
Canada	538/2061 (25.4)	0.90 (0.78–1.04)
<b>I am too busy to make time to go to the doctor</b>		
UK	1522/6942 (22.8)	1.00 (Reference)
England	497/2350 (22.8)	
Northern Ireland	519/2300 (23.5)	
Wales	506/2292 (23.1)	
Denmark	345/1997 (17.4)	0.68 (0.58–0.79)
Norway	414/2001 (20.8)	0.87 (0.75–1.01)
Sweden	380/2034 (19.2)	0.81 (0.70–0.94)
Australia	860/3981 (23.7)	1.04 (0.91–1.18)
New South Wales	429/1994 (23.6)	
Victoria	431/1987 (23.7)	
Canada	586/2062 (29.4)	1.35 (1.15–1.58)

Percentages and odds ratios for all UK countries combined, Denmark, Norway, Sweden, both Australian states combined and all Canadian provinces combined are weighted for unequal sampling fraction by country (UK), state (Australia) or province (Canada). All percentages and odds ratios are weighted for different probabilities of selection by household size.

<sup>a</sup>Directly age-sex standardised using European Standard Population.

<sup>b</sup>Adjusted for age and sex.

living alone, self-rated health and experience of cancer, and weighting for non-representativeness, made little difference to the pattern of results.

There were large international differences in the proportions knowing that 70-year olds were at greater risk of cancer than younger people (Table 3). Awareness of age-related risk was the lowest in the UK (14%; and especially low in Northern Ireland and Wales) and the highest in Sweden (38%). Canada and Australia had similar levels of awareness of age-related risk compared with the UK. Controlling for education attenuated the size of the differences slightly, but the pattern remained the same. Controlling for living alone, self-rated health and experience of cancer, and weighting for non-representativeness, made little difference to the results.

**Beliefs about barriers to symptomatic presentation and about cancer outcomes.** People in the UK were most likely to report that embarrassment would put them off going to the doctor with a symptom that might be serious (15%) and those in Denmark the least likely (6%) (Table 4). People in the UK were also most likely to report that worry about wasting the doctor’s time would put them off going to the doctor (34%) and those in Sweden the least likely (9%). People in the UK were also most likely to report that worry about what the doctor would find might put them off going to the doctor (28%), although the international differences were less marked: people in Norway were least likely to report this (20%). People in Canada were most likely to report that being too busy would put them off going to the doctor (29%) and those in Denmark the least likely (17%). Using the aggregate score, Denmark had the lowest mean barriers to symptomatic presentation (4.95/50), followed by Sweden, Norway, Australia and Canada (Table 5). The UK had the highest mean barriers to symptomatic presentation (8.29/50).

Very high proportions of people agreed that cancer could often be cured, with those in Sweden and Norway most likely to agree, and those in Australia and Canada least likely to agree (Table 6). Similarly, a high proportion of people disagreed that a diagnosis of cancer was a death sentence and agreed that people with cancer could expect to continue with normal activities and responsibilities, with small differences between countries. There were also small differences between the countries in beliefs about cancer outcomes score: Norway had the lowest mean score (9.72/50; fewer negative beliefs) and Australia the highest (12.82/50; more negative beliefs) (Table 5).

For both sets of analyses, controlling for age, sex, education, living alone, self-rated health and experience of cancer, and weighting for non-representativeness, made little difference to the pattern of results.

DISCUSSION

People in the UK, which has relatively poor cancer survival, had lower awareness that the risk of cancer increases with age and reported more barriers to symptomatic presentation (especially worry about wasting the doctor’s time) than other countries. However, people in Denmark, who also have relatively poor cancer survival, had high awareness of age-related risk of cancer and few barriers to symptomatic presentation. Awareness of cancer symptoms was high and beliefs about cancer outcomes were positive for all participating countries and differences between the countries were small. We found no evidence that the overall pattern of cancer awareness and beliefs followed the overall pattern of 1-year cancer survival across the countries.

To our knowledge, this is the first study examining differences in cancer awareness and beliefs between high-income countries. It is unlikely that methodological limitations explain the results. We developed harmonised versions of the ABC to measure the

constructs in each country and harmonised the survey methods, using a single provider to carry out the sampling and interviews. We achieved samples that were representative, in terms of age, sex and education, of the underlying populations. Controlling for any differences in age, sex and education distribution between populations and doing sensitivity analyses to allow for under-representativeness of certain demographic groups made very little difference to the results. The large sample sizes meant that we were confident about the precision of our estimates, although it also meant that small differences were statistically significant even where actual differences were not likely to be of great public health significance. Moreover, where proportions reporting an outcome are high (e.g., in beliefs about cancer outcomes), odds ratios become unreliable as measures of relative risk (Davies *et al*, 1998). In view of this, our approach to interpreting the results was to focus on absolute differences between the countries that were likely to be of public health significance.

There was some variation in estimated response rates between countries, with lower rates in the Scandinavian countries and the highest rate in Australia. It is difficult to know whether the response rates achieved in Australia, Canada and the UK are comparable to other surveys, because few reports of random digit dialling surveys in these countries have reported response rates according to AAPOR conventions. In Scandinavian countries, where there are population registers, telephone surveys often achieve higher response rates than this, but it is more usual for the researchers to write to people before telephoning them (e.g., Feveile *et al*, 2007). We chose not to write to potential participants in advance in the Scandinavian countries, because it would have increased the variation in survey methods. Despite the variation in response rates, the age distribution of the samples were broadly similar to the national populations except for some differences in gender balance (more women) and higher levels of education (which often happens in health surveys). However, weighting made little difference to the estimates of cancer awareness or beliefs that suggests that under- or over-representation of particular groups did not significantly influence the pattern of cancer awareness and beliefs.

Table 5. Beliefs about barriers to symptomatic presentation and cancer outcomes – aggregate scores		
	Mean score out of 50 (95% CI)	
	Barriers to symptomatic presentation	Negative beliefs about cancer outcomes
UK	8.29 (7.87–8.72)	11.14 (10.71–11.58)
England	8.85 (8.33–9.38)	10.75 (10.21–11.29)
Northern Ireland	9.30 (8.75–9.86)	11.93 (11.37–12.48)
Wales	9.21 (8.59–9.83)	11.11 (10.55–11.68)
Denmark	4.95 (4.59–5.31)	12.66 (12.19–13.13)
Norway	5.28 (4.90–5.66)	9.72 (9.25–10.19)
Sweden	5.29 (4.95–5.64)	12.06 (11.63–12.52)
Australia	5.92 (5.58–6.26)	12.82 (12.38–13.25)
New South Wales	6.65 (6.06–7.25)	12.48 (11.72–13.23)
Victoria	6.52 (5.97–7.08)	12.18 (11.49–12.87)
Canada	6.52 (6.06–6.98)	12.39 (11.84–12.93)

Abbreviation: CI = confidence interval. Note: a higher score on barriers to symptomatic presentation indicates more barriers; a higher score on negative beliefs about cancer outcomes indicates more negative beliefs about cancer outcomes. All means adjusted for age and sex. Means for all UK countries combined, both Australian states combined and all Canadian provinces combined are weighted for unequal sampling fraction by country (UK), state (Australia) and province (Canada). All means are weighted for different probabilities of selection by household size.

Table 6. Beliefs about cancer outcomes – individual items

	n (%) <sup>a</sup>	OR (95% CI) <sup>b</sup>
<b>Agree with 'Cancer can often be cured'</b>		
UK	6228/6796 (92.8)	1.00 (Reference)
England	2108/2290 (92.8)	
Northern Ireland	2086/2251 (92.8)	
Wales	2034/2255 (90.4)	
Denmark	1786/1960 (91.0)	0.81 (0.65–1.00)
Norway	1872/1979 (94.6)	1.38 (1.08–1.77)
Sweden	1887/2006 (94.0)	1.25 (0.98–1.58)
Australia	3422/3844 (88.9)	0.65 (0.54–0.78)
New South Wales	1703/1926 (88.7)	
Victoria	1719/1918 (89.3)	
Canada	1768/2028 (88.3)	0.59 (0.47–0.72)
<b>Disagree with 'A diagnosis of cancer is a death sentence'</b>		
UK	4885/6629 (77.4)	1.00 (Reference)
England	1706/2231 (77.8)	
Northern Ireland	1531/2200 (69.5)	
Wales	1648/2198 (75.8)	
Denmark	1435/1954 (73.6)	0.82 (0.71–0.94)
Norway	1500/1959 (76.5)	0.95 (0.82–1.09)
Sweden	1559/2020 (77.2)	0.99 (0.86–1.14)
Australia	2785/3787 (73.7)	0.83 (0.74–0.94)
New South Wales	1406/1906 (73.9)	
Victoria	1379/1881 (73.4)	
Canada	1519/2018 (75.4)	0.92 (0.79–1.08)
<b>Agree with 'People with cancer can expect to continue with normal activities and responsibilities'</b>		
UK	6115/6680 (92.6)	1.00 (Reference)
England	2074/2256 (92.7)	
Northern Ireland	2023/2218 (91.8)	
Wales	2018/2206 (91.8)	
Denmark	1687/1929 (87.6)	0.55 (0.45–0.68)
Norway	1864/1972 (94.4)	1.36 (1.07–1.74)
Sweden	1816/1971 (92.2)	0.92 (0.74–1.15)
Australia	3421/3806 (90.0)	0.73 (0.61–0.88)
New South Wales	1689/1905 (89.0)	
Victoria	1732/1901 (91.2)	
Canada	1778/2023 (88.8)	0.92 (0.74–1.15)
Abbreviation: CI = confidence interval. Note: an odds ratio > 1 indicates less negative beliefs about cancer. Percentages and odds ratios for all UK countries combined, both Australian states combined and all Canadian provinces combined are weighted for unequal sampling fraction by country (UK), state (Australia) or province (Canada). All percentages and odds ratios are weighted for different probabilities of selection by household size.		
<sup>a</sup> Directly age–sex standardised using European Standard Population.		
<sup>b</sup> Adjusted for age and sex.		

We calculated aggregate scores for two sets of items (beliefs about cancer outcomes and about barriers to symptomatic presentation), because factor analysis provided strong evidence that responses to each set of items were driven by common underlying factors: broad perceptions about either beliefs about cancer outcomes or barriers to symptomatic presentation (Simon *et al*, 2012). The mean differences between countries in the aggregate scores are more likely to represent real differences and are more precise (with narrower confidence intervals) than the responses to the individual items.

We monitored the three most widely distributed national newspapers in each of the participating countries for 2 weeks before and during fieldwork, focusing on stories or campaigns that would have affected all or most of the geographical area covered reported in the first three pages. In Denmark and Norway, there were no relevant news stories. In Sweden, there were stories about breast screening, HPV vaccination and the quality of cancer care. In the UK, there was a story about a blood test to identify ovarian cancer early, and a negative story about the quality of cancer care in the NHS. In Canada, there was a story about a celebrity with oral

cancer but no details about symptoms, and a story about the quality of care in cervical screening. In Australia, there were stories about men's health checks for a range of health issues (not just cancer), dietary risk factors for cancer and mammography. Although we cannot rule out an effect of these stories on our results, none appeared sufficiently specific to have influenced population levels of cancer awareness or beliefs to the extent that they would explain any observed international differences.

The biggest differences in cancer awareness and beliefs between the participating countries were in beliefs about barriers to symptomatic presentation and awareness of age-related risk, with the UK having the highest level of barriers and the lowest awareness of age-related risk; this is consistent with previous UK surveys (Robb *et al*, 2009; Forbes *et al*, 2011). Our study was not designed to address the underlying reasons for international differences; that would be for future studies. We speculate that people's worry about wasting the doctor's time in the UK could be shaped by a belief that they might be told they were wasting the doctor's time if they presented, that others might judge that they



should not waste the doctor's time or that they should not waste public resources. British people could be more concerned about embarrassment because of the traditional 'stiff upper lip'. Barriers to symptomatic presentation in Britain warrant further research to inform interventions to promote early presentation.

The pattern of differences in cancer awareness and beliefs between the participating countries did not follow the pattern of differences in survival, but there was some evidence that it followed cultural/language demarcations: Scandinavian people had lower levels of barriers to symptomatic presentation and better awareness of age-related risk than people in the Commonwealth countries, but further studies are needed to identify the origins of these differences.

Although we found no evidence that the international pattern of cancer awareness and beliefs followed the 1-year survival pattern, our results do not rule out an association between cancer awareness and beliefs and cancer survival at an individual level, because it was an ecological analysis looking at average levels of cancer awareness and beliefs.

Other factors, for example, delay in primary care referral or delay in diagnosis in secondary care, may contribute to delay in diagnosis. It has been hypothesised that poor cancer survival in Denmark is related to gate-keeping by primary care doctors (Vedsted and Olesen, 2011), although a Danish study found that a large proportion of delay in diagnosis was attributable to delay between the GP initiating investigations for cancer and the start of treatment (Hansen *et al.*, 2011). Furthermore, other analyses from the ICBP exploring stage and survival data for ovarian (Maringe *et al.*, 2012) and breast cancer (Michel Coleman, personal communication), suggest that differences in access to treatments or tumour biology may also be having a role in differences in survival rates, although differences in staging procedures make comparisons difficult. All these issues – beliefs and behaviours in primary care, diagnostic pathways and availability of treatments – are now being studied across the ICBP countries. This will help to work out the relative importance of each factor in determining the 1-year cancer survival rates in each country.

Our findings have some specific implications for individual countries. In Denmark, poor 1-year cancer survival rates are not likely to be due to poor cancer awareness and negative beliefs in the population, and the causes must be sought elsewhere. In the UK, interventions to promote early presentation might usefully focus on addressing awareness of the age-related risk and increasing the public's confidence to approach the GP with possible cancer symptoms.

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## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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## APPENDIX A

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